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AUTHOR Barton, Len
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ABSTRACT

This paper raises issues relating to disability and citizenship, especially those concerned with difference, discrimination, power, and the politics of identity. It adopts a social model of disability that is critical of individualized, homogenized, deficit views of people with disabilities and urges an equal opportunities approach in which the demands for civil rights, choice, participation, and antidiscrimination legislation are essential components. The paper argues that, historically, people with disabilities have been fundamentally excluded from citizenship; they have been viewed as subhuman and therefore unworthy or unable to experience the entitlements and responsibilities associated with citizenship. The need for schools at all levels to provide inclusive services and involve people with disabilities in discussions and decisions that will empower them to exercise the rights of citizenship in the future is examined. (Contains 44 references.) (DB)

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CITIZENSHIP AND DISABLED PEOPLE: A DISCOURSE OF CONTROL?

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Professor Len Barton
Division of Education
University of Sheffield

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Disability, Dependency and Control

The issue of disability is connected to questions of status. Thus, how disability is defined, by whom, and for what purposes, are all important questions needing to be carefully explored. They are important, for example, in helping to ascertain the extent to which official definitions and decision-making take the voices of disabled people seriously and thereby legitimise positive or negative images through particular policies and provisions. With regard to the latter, they may give us some purchase on the reasons why disabled people do not experience the benefits of real citizenship (Finkelstein 1993; Oliver 1993)

In order to achieve an adequate understanding of the status of disabled people it is essential to consider the key historical antecedents which have helped to shape current definitions of both an official and common-sense level of understanding. This includes asking questions about specific policy provisions such as:

- What view of disability do they perpetuate?
- Whose interests do they serve?
- On what basis are they justified?
- What are the outcomes for those they claim to support?

Approaching the question of citizenship in relation to disabled people necessitates engaging with the issue of power. This involves degrees of freedom, choice and participation. These are expressed within

asymmetrical sets of social relationships which influence how we relate to, and may effect one another. Thus as Bauman (1990) maintains:

> To have power is to be able to act more freely; but having no power, or less power than others have, means having one's own freedom of choice limited by the decisions made by others (p.113).

Disability is a significant means of social differentiation. To be disabled means to be discriminated against and involves experiencing varying degrees of stereotyping, social isolation and restriction (Oliver 1990; 1995). This perspective is a key aspect of a social model of disability, one which seeks to identify the ways in which society disables people. The task then is to remove those disabling material, economic, ideological, attitudinal barriers that cumulatively prevent disabled people from experiencing the entitlements of citizenship. This includes challenging the mythology of the rhetoric of democracy in the light of the position and experiences of marginalised and oppressed groups (Abberley 1987).

A significant feature of the oppression of disabled people is the extent to which their voice has been excluded from developments and decisions affecting their lives. An historical perspective is important in helping us understand this situation.

The conditions and factors which have influenced the status of disabled people have changed over time. Historically, a medical model of disability has powerfully influenced policy and practice. In this approach an emphasis is placed on an individual's loss, inabilities, inferior condition or syndrome. From this approach strong custodial measures have been viewed as the most appropriate response for those individuals who were

defined, as a menace needing total institutional provision, or a burden needing sterilising and even exterminating and as vulnerable thus in need of protection (Scull 1982; Wolfensberger 1993; Tomlinson 1982; Ryan & Thomas 1980).

Official definitions often enshrined in legislation are an important indicator of the marginalisation of oppressed groups. Various labels have been used to define them including: 'deformed', 'invalid', 'spastic', 'cripple', 'feeble-minded', 'mad', 'idiot', 'lunatic' and 'subnormal'. Historically, they have been essentially powerless and the 'objects' of decisions made by significant others claiming to act on societies and/or their behalf.

A very significant factor of the history of disabled people has involved them being the recipients of policies and practices legitimating models supporting custody-control, personal-tragedy conceptions of the individual as well as being objects of charity.

Disabled people's history needs to be viewed as one of an increasing struggle to establish and maintain positive self-identities. This includes an unwillingness to acquiesce to a subordinate role or stigmatised identity. It is about developing self-respect, self confidence and solidarity with other disabled people. This is part of their struggle for rights, choice and participation in society. Essential to this form of action is the demand for anti-discrimination legislation (Shakespeare 1993; Barnes & Oliver 1995; Barnes 1996). This is a crucial but not sufficient factor for achieving citizenship.

Issues of equality and citizenship are central concerns in the process of emancipation because as (Rioux 1994) notes:

> Disability is not measles. It is not a medical condition that needs to be eliminated from the population. It is a social status and the research agenda must take into account the political implications attached to that status (Rioux 1994) (pp.6 - 7).

Disability is thus a social and political category in that it includes practices of regulation and struggles for empowerment and rights (Fulcher 1989).

Portrayals of disabled people as passive, incomplete and unfortunate, inhibit the development of conceptions which view such people as actively seeking to change their circumstances. Alternatively, portraying disabled people as heroic/heroine figures minimises the very real costs of oppression and underplays the importance of group effort and solidarity. Both these perspectives are offensive and counter productive to the fundamental changes required for the removal of disabling barriers. Nor, must it be assumed that 'disability' is a unitary category involving conceptions of sameness. This would be to minimise the degree to which, for example, class, race, gender and age factors cushion, and or, compound the experience of disability. Through this means some disabled people experience **simultaneous** forms of oppression (Stuart 1992).

An individual's impairment must not be viewed as determining the degree of independence that person may exercise. This should not be taken to imply that disabled people do not experience pain or need medical support. Rather, the issue is the grounds on which that is provided and the forms of social relationships that are involved. Questions concerning power-relations, expertise and choice are central to this issue.

Citizenship, Human Rights and Disability

The demands for citizenship needs to be set against the stubborn realities of unequal social conditions and relations which disempower and disenfranchise disabled people (Finkelstein 1993). Institutional discrimination is still a powerful force to be engaged with as can be seen from the following factors:

> Segregated provisions tend to encourage negative labels, suspicion, stereotypes and ignorance of a reciprocal nature (Morris 1990; Barnes 1991).
>
> The ideology of 'caring' for someone which underpins practice in the social and health services, predominately means 'taking responsibility for them, taking charge of them (p.38)'. This necessarily involves relations of dependence and contributes to a custodial notion of caring (Morris 1993).
>
> Little opportunity exists for disabled people to define the issues relating to Community Care which they think are important (Bewley and Glendinning 1994).
>
> Disabled people are more likely to be out of work than their non-disabled counterparts (Barnes 1991).
>
> Those who do work tend to find themselves in poorly-paid, low-skilled and low-status jobs (Helander 1993).
>
> Disabled people experience conditions of life inferior to those of the rest of the population. Thus there is a close association between disability and poverty (Coleridge 1993).

The focus of criticism and concern therefore needs to move from an individualised, deficit approach, to one in which institutional barriers can

be challenged and the rights and value of disabled people as equal citizens be achieved.

A commitment to human rights is based on the belief that the world is changeable and disability as a human rights issue reinforces the importance, as Starkey (1991) advocates:

> ...that differences, physical or cultural, should have no bearing on a person's entitlement to freedom, equality and dignity (p.27).

In a discussion of disability issues in relation to the European context, Daunt (1991) supports this position and argues for the establishment of two complimentary principles:

1. The principle that all measures should be founded on the explicit recognition of the **rights** of disabled people.

2. The principle that all people are to be regarded as of **equal** value in the society and to the society (p. 184).

The importance of such principles and their implementation are related to the extent to which, on the one hand, we recognise the seriousness of the discrimination which disabled people experience and, on the other, acknowledge that the exercise of citizenship rights is independent of their economic contributions (Rioux 1994).

Citizenship, Disability and Difference

In attempting to understand some of the key issues involved in the question of democracy and citizenship it is important, for example, to distinguish between the content, style and function of political rhetoric and the lived-reality of individuals or groups within specific socio-economic conditions and relations. This provides an added incentive for recognising as Turner (1993) contends, that citizenship is necessarily and fundamentally concerned with issues of inequality and the distribution of resources in society. Thus, in the quest for citizenship and democratisation existing social and political inequalities and power differentials have to be challenged and changed.

From this perspective citizenship is to be viewed as a contested concept. Within a society characterised by gross inequalities disputes arise between and within groups over the criteria governing the use of citizenship, the kinds of rights involved, how membership is determined and the kind of obligations binding upon a citizen (Carr and Harnett 1996). These and other factors constitute the focus of reflection and debate, through which the relationship between the citizen and state is redefined.

Difference is now to be viewed as a challenge, a means of generating change and an encouragement for people to question unfounded generalisation, hostility, prejudice and discrimination. This challenge needs to be viewed in terms of excluded groups themselves as well as a means of questioning and changing the perspectives of dominant groups. This fundamental task is to develop a vision of democracy through difference (Phillips 1993).

In the pursuit of social justice, participatory democracy and citizenship the denial of difference needs to be resisted. Learning to live with one another necessarily involves learning to respect our differences. Part of this development also includes dealing with the issue of self-oppression. This process of empowerment enables people to have pride in themselves, in who they are. In a sensitive and personal self analysis Corbett (1994) provides some vivid insights into the difficulties and benefits of challenging stereotypes, discrimination and negative feelings of inferiority or personal inadequacy. Whilst the ultimate goal is the realisation of a valued and dignified identity, she maintains that the pressures to conform or be 'normal' are extremely powerful.

Conclusion

In this paper we have briefly raised some of the important issues concerning the question of disability and citizenship. We have adopted a social model of disability which is critical of individualised, homogenised, deficit views of disabled people. The struggle for citizenship entails engaging with issues of difference, discrimination, power and the politics of identity. This we maintain needs to be part of an equal opportunities approach in which the demands for civil rights, choice, participation and anti-discrimination legislation are essential components. Such a process of empowerment and critique necessarily involves the development of political awareness and action.

We have argued that historically disabled people have been fundamentally excluded from concerns over citizenship for several reasons. They have been viewed as a sub-human species and therefore unworthy or unable to experience the entitlements and responsibilities associated with

citizenship. They have been viewed as a menace or threat and therefore have forfeited any possible rights or entitlements. Finally, as a result of the extent of institutional discrimination in their lives, they have been so dependent and socially disadvantaged that they have been unable to experience the exercising of true citizenship.

The role schools and teachers play in the pursuit of a barrier free society is an important one. The extent to which the impact of marketisation on educational planning and provision will militate against the introduction and effective implementation of 'education for all' values and practices, is an issue of very serious concern (Ball 1993). Segregated special school provision has historically served to encourage stereotypes, ignorance and suspicion of a reciprocal nature between disabled and non-disabled people (Morris 1990; Rieser & Mason 1990; Barnes 1991). Dealing with this particular barrier of exclusion will be an important task. Nor is the issue merely at the level of schools. Changes are required within post-school education including higher education (Corbett & Barton 1992; Hurst 1996). Involving disabled people in discussions and decisions over these issues will be vitally important and a further means of their participation over factors affecting their lives.

Listening to the voices of disabled people is absolutely essential as they increasingly express their criticisms, needs and demands. The celebration of difference with dignity is being expressed through their songs, poetry, writings and other art forms. Yet there is no room for complacency. Part of the frustration that disabled people and their organisations experience is the result of the failure of the so-called democratic-system to listen, or take their views seriously. Part of the response to this situation has been groups of disabled people taking to the streets to protest and undertake

various acts of civil disobedience. Some of the most powerful examples of these actions have been the protests during the raising of monies for Telethon and recent attempts to gain Anti-discrimination Legislation through Parliament. Such demonstrations were inspired by their refusal to be viewed as objects of charity and their demands for real citizenship and participatory democracy.

A fundamental aspect of a democracy is the opportunity and encouragement to exercise freedom of speech, debate and dialogue. Part of the task as Phillips (1993) notes is to develop a form of political discourse that will enable **all** citizens to participate in this process. Any discussions concerning the sort of society this will entail and the forms of social change that will require, must include disabled people and or their advocates. Only through this means will we begin to recognise their rights and value them as equal citizens.

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